2006
'Unmet Need'
Needs Assessment Report

Ryan White Title I
Phoenix Eligible Metropolitan Area

Prepared for:

The Phoenix HIV Health Services Planning Council

Prepared by:

COLLABORATIVE RESEARCH
www.collaborativeresearch.us

September 2006

TABLE OF CONTENTS

2006 Unmet Needs Assessment

Phoenix EMA HIV Health Services Planning Council *September 2006*

Executive Summary

Throughout the epidemic in Arizona, the majority of *emergent* HIV infections have been among males who comprise 88.2% of all confirmed emergent HIV infections and 86.7% of current estimated prevalence. Arizona estimates that currently 1 in 10 Males who have Sex with Males (MSM) statewide are infected with HIV and nearly 1 in 4 between the ages of 35 and 49 years. Maricopa and Pinal counties together include 77% of the state's population; 88% of MSM HIV/AIDS prevalence; and 90% of MSM emergent HIV infection. (2005 Integrated Epidemiologic Profile)

MSM of color (and particularly African American MSM) are disproportionately affected by HIV. In Maricopa County, for every 1.28 MSM "In Care" there is one MSM "Out of Care". In Pinal County, for every .96 MSM "in Care" there is one MSM with "Unmet Need".

In Arizona, the emergent cases of Injection Drug Use (IDU) appear to be on the decline, decreasing from 24.8% of all emergent infections during 1994-1998 to 22.6% during 1999-2003. Eighty two percent (82%) of all prevalent and emergent infections among IDU are male and 58% of the prevalent IDU cases are among Whites. The majority of IDU-related infections are found in the urban counties (Maricopa and Pima); however, Pinal County (a rural county) has twice the proportion of emergent IDU cases as its proportion of the state population. HIV positive IDU are less likely to be in care and services than HIV positive MSM. In Maricopa County where 60% of all IDU HIV/AIDS cases are reported, there are 1.03 persons in care for every one who is not in care. In contrast, in Pinal County, for every one HIV positive IDU who is out of care, there is .82 IDU in care. (2005 Integrated Epidemiologic Profile)

High Risk Heterosexuals (HRH) make up 10.3% of prevalent HIV/AIDS cases and 13.1% of emergent infections in Arizona. HRH is on the increase, up from 9.31% of all HIV/AIDS diagnoses from 1994-1998 to 11.3% among persons aged 30-39 years during 1999-2003. Among HRH, females outnumber male cases by a ratio of nearly 2.5 to 1 among prevalent cases and 2:1 among emergent cases.

Whites make up the greatest number of cases of HRH, but as with MSM and IDU, minorities are disproportionately affected. (2005 Integrated Epidemiologic Profile) For every 1.32 HRH "In Care" in Maricopa County, there is one HRH "Out of Care". In Pinal County, for every .89 HIV positive HRH in care, there is one HRH out of care.

(See Table 1 on the following page for unmet need estimates by risk, by county in the Phoenix EMA, according to the 2005 Integrated Epidemiologic Profile)

Table 1: Unmet Need Table: Unmet Need by County by Transmission Risk

	2003 IN CARE			*2003 UNMET NEED*			*Ratio*	*EST. 2003 Risk POPULATION*	
COUNTY	**MSM* CASES**	**%**	***Rate Per 100 MSM***	**MSM* CASES**	**%**	***Rate Per 100 MSM***	***In Care/ Unmet Needs***	***MSM POPULATION***	**MSM POP. DENSITY**
MARICOPA	2629	73.6	6.05	2054	69.5	4.73	1.28	43,467	4.71
PINAL	69	1.9	2.60	72	2.4	2.72	0.96	2,650	0.49
TOTAL	**3571**	**100.0**	**4.98**	**2955**	**100.0**	**4.13**	**1.21**	**71,609**	**0.63**
	IDU Cases	**%**	***Rate Per 100 IDU***	**IDU Cases**	**%**	***Rate Per 100 IDU***		***IDU POPULATION***	**IDU POP. DENSITY**
MARICOPA	720	68.7	1.98	698	60.4	1.92	1.03	36,331	3.94
PINAL	53	5.1	2.39	65	5.6	2.93	0.82	2,215	0.41
TOTAL	**1048**	**100.0**	**1.75**	**1156**	**100.0**	**1.93**	**0.91**	**59,855**	**0.53**
	HRH Cases	**%**	***Rate Per 100 HRH***	**HRH Cases**	**%**	***Rate Per 100 HRH***		***HRH POPULATION***	**HRH POP. DENSITY**
MARICOPA	369	71.4	0.70	279	60.7	0.53	1.32	53,048	5.75
PINAL	17	3.3	0.53	19	4.1	0.59	0.78	13,983	1.52
TOTAL	**517**	**100.0**	**0.59**	**460**	**100.0**	**0.53**	**1.12**	**87,395**	**0.77**

Challenges the "Out of Care" Population Presents to the Service Delivery System

Based upon the unmet need survey data, it may be inferred that the 'Out of Care' population in the Phoenix EMA is 75% Male and 25% Female. As much as fifty five percent (55%) of the population is likely to be homeless or temporarily housed. The majority are more likely than not to be HIV positive/not AIDS diagnosed. And, based upon the R.A.R.E. survey study, the majority is actively using illicit substances, many of whom report regular use of crystal methamphetamine. In fact, the majority of OOC PLWHA report "active substance abuse" as the primary reason for their delay into primary medical care and/or their major reason for stopping HIV primary medical care.

The crystal methamphetamine problem is recognized as a significant contributor to increases in risky sex and higher rates of HIV transmission and other STDs among MSM. According to the CHEST study, MSM who use crystal meth are three times more likely to contract HIV through receptive anal intercourse than MSM who do not use the drug. The use of crystal meth is associated with poor adherence to antiretroviral therapy, likely resulting in increased viral loads and increasing risk for other illnesses. Research also strongly suggests that the drug can adversely interact with HIV medications and possibly even cause death. (NASTAD, November 2004) When continuously used by OOC MSM, the risk for further transmission of HIV disease to negative sexual and drug using partners is magnified.

The Phoenix OOC population includes those who have been erratically in care, those who have dropped out of care for periods of one year and for greater than two years duration, and those who have yet to enter primary HIV medical care. The OOC survey group reported a high level (65%) of co-morbidity with STDs and chronic health conditions. ***By far, the single greatest variable that***

negatively impacts successful entry into and retention into HIV primary medical care is substance use and abuse. Crystal methamphetamine is the single drug of choice most frequently reported as used by the OOC population.

Service Gaps of the Out of Care Population

The top six ranking service NEEDS and GAPS reported by the entire 'Out of Care' respondent group include primarily 'supportive services': Housing, Clothing, Food, Translation services, and Transportation. Hospitalization is also listed as a needed service. (It is not clear from the data whether this service relates to physical health issues or substance abuse treatment needs.) A lack of awareness of exact service location and/or how to access needed services and the lack of funding/insurance/underinsurance are cited by OOC respondents as reasons impeding access to care and services. Lack of translation is perceived to be at least part of the reason for the perceived unavailability of needed housing services. *The 'motivators' most frequently cited by the OOC population which would prompt re-entry into care included "Substance Abuse Treatment",* "Transportation", "Higher quality services", and "Better trained physicians and nurses".

Estimated Costs Associated with Delivering Services to the Out of Care Population

The Special Population of 'Out of Care' PLWHA represents a significant and increasing burden on the existing systems of care. The primary care needs will include all of the required comprehensive services for a population with a high rate of co-morbidities. The needs assessment data indicates that this population will also require a great deal of life stabilizing intervention, including meeting the unmet needs for stable housing, food, clothing and transportation, prior to and on a continuous basis in order to strengthen entry, engagement and retention in primary care. The Phoenix EMA Case Managers will be challenged to draw on all available Ryan White and other local resources in order to coordinate the supportive service needs of this special population upon entry into care and, likely, on an ongoing basis for some time.

This special population inherently represents a higher behavioral risk group, engaging in elevated levels of risky and unprotected sex while using substances, and reporting more unprotected sexual encounters with more sexual partners than other special populations, overall. Therefore, these individuals are likely to benefit from intensive prevention case management/CRCS services in order to prevent further transmission of HIV to others and reduce their own potential acquisition of STDs and resistant strains of HIV. Funding through CDC in collaboration with Ryan White and other funding resources will be necessarily expanded to serve this growing need.

Last, but certainly not least, the substance abuse treatment needs of the OOC population must be addressed if these individuals are to be successfully enrolled into primary care and able to adhere to ART medications. In-patient substance abuse treatment may be absolutely essential to successfully treat a significant minority of the substance-abusing OOC population. Local state, federal and private funds will be utilized to support these service needs, though waiting lists may be lengthy. The majority of the substance-using OOC population may respond to outpatient substance abuse treatment, fundable through Ryan White and other local resources.

I. Introduction

A. Background

Annual Needs Assessments are studies conducted to canvass the HIV/AIDS client base and determine service gaps and barriers in the continuum of care for Persons Living With HIV/AIDS (PLWHA). Results of this client-centered activity are used to establish service priorities, document the need for specific services, determine barriers to accessing care, provide baseline data for comprehensive planning, including capacity building, and help providers improve the access and quality of service, especially to Severe Need Groups (SNGs)[1] and Special Populations[2] Severe Need Groups/Special Populations are demographic/exposure subsets of the community who are disproportionately impacted by the epidemic and/or at high risk for unmet need.

A recent focus of the Annual Needs Assessment process is to survey PLWHA who are "Aware and Not in Care"[3] and determine their unmet needs. PLWHA failing to access primary medical care for a period of time exceeding one year are deemed 'Out of Care'. Primary Medical Care is technically defined as the receipt of one or more of three forms of service—use of (1) antiretroviral drugs (2) CD4 lab tests and (3) Viral Load lab test.[4] The Phoenix EMA considers an individual with HIV or AIDS to have an unmet need for care (or to be 'Out of Care') when there is no evidence that the person received any of the above forms of service during a defined 12 month time frame.

In Spring 2006, the Phoenix HIV Health Services Planning Council contracted with Collaborative Research to conduct an 'Out of Care' needs assessment to further assess unmet need among targeted individuals living with HIV/AIDS who are 'Out of Care' in the Phoenix Eligible Metropolitan Area. "Unmet Need" specifically refers to the need for HIV-related primary health care. The need for other services is referred to as "Service Gaps".

The CARE Act Amendments of 2000 require Ryan White CARE Act Title I and Title II Grantees and planning bodies to determine how many people in their service area know they are HIV positive but are not receiving regular HIV-related primary medical care. The ultimate goal of the unmet need process is to get the 'Out of Care' into care and retain them in care. The three major process steps for addressing unmet need include:

1. Estimating the number of people in each service area who know they are HIV-positive but not receiving HIV-related medical care: the number NOT "in care".

Severe Need Groups: 1) Anglo MSM; 2) African American MSM; 3) Intravenous Drug Users; 4) Substance Abusers; 4) Women of Childbearing Age; 5) Incarcerated/Recently Released; 6) Youth ages 13-24.

[2] Phoenix Title I EMA Special Populations include: Hispanics; MSM; African Americans; Incarcerated/Recently Released; American Indians; and Rural PLWHA.

OOC & Aware: CDC estimate of 850-900,000 currently HIV positive, 2/3 or 670,000 know they are infected. Of this, 1/3 or 233,000 do not receive HIV-related primary health care (CDC, February 2002)

1) CD4 – CD4 (T4) or CD4 + CELLS. HIV's preferred target cells. Destruction of CD4+ lymphocytes is the major cause of the immunodeficiency observed in AIDS, and decreasing CD4+ lymphocyte levels appear to be the best indicator for developing opportunistic infections.

2) VIRAL LOAD TEST - Test that measures the quantity of HIV RNA in the blood. Results are expressed as the number of copies per milliliter of blood plasma.

3) ANTIRETROVIRAL DRUGS -

2. Assessing the service needs and barriers to care for such people, including finding out whom they are and where they live.
3. Addressing unmet needs by finding these individuals and getting them into care. (HRSA/Mosaica Unmet Need TA Center, 2006)

Based upon the Unmet Need Framework, the Phoenix EMA undertook a rapid needs assessment process in order to begin to address the following four items, including any plans for cross-Title collaboration in these areas:

1. *Describe the demographics and location of persons who know their status and are NOT in care;*
2. *Assess the service needs, gaps and barriers to care, including disparities in access and services among affected subpopulations and historically underserved communities;*
3. *Describe plans to find people NOT in care and get them into care; and*
4. *Describe how the results of the Unmet Need Framework were used in planning and decision-making about priorities, resource allocations and the system of care.*

This Unmet Need Report is organized around addressing Items 1 and 2 above.

B. Relevance of an Unmet Need/Out of Care Study

Approximately one-third of PLWHA in the United States are aware that they are HIV-positive but do not access primary medical care as defined by the triad of antiretroviral therapy, CD4 and Viral Load laboratory monitoring tests at least every 12 months. The Centers for Disease Control (CDC) estimate that approximately 233,000 of 670,000 Americans who know their HIV status are not regularly receiving HIV primary medical care. (CDC: Ninth Conference on Retroviruses and Opportunistic Infections, Seattle, Washington, February 2002) Reasons for being Out of Care differ, but occur and re-occur at points along the Continuum of Care. ***The current "Out of Care" estimate for the Phoenix EMA Title I service area is 3,563 persons (based on the EMA's Unmet Need Framework constructed by the Arizona Department of Health Services, 2005)***

Four (4) subgroups exist among the 'Out of Care', two of whom do not technically adhere to the HRSA definition of at least one year not accessing primary medical care, but do shed insight into the 'Out of Care' issue. The four (4) groups are: 1) Newly diagnosed (risk of 'ever' attaching to care); 2) Those at 'risk of going Out of Care' (over 6 months not accessing primary medical care, display warning signs of non-compliance with treatment regimens); 3) the 'Technically Out of Care' (over 12 months not accessing primary care); and, 4) the Never in Care.

The initial and significant burden is attaching persons to care immediately upon a positive HIV diagnosis. This juncture is one that many PLWHA recount as 'shock', 'disbelief', 'denial' and often, if co-afflicted with mental health and/or substance abuse issues, regress to numb themselves from the diagnosis. Curiously, the recent advances in HIV treatment, especially Antiretroviral (ARV) Therapy have resulted in person's newly diagnosed taking the news lightly under the misguided assumption that HIV medications can quickly relieve any sickness. These individuals tend to not enter care until they 'feel sick'. In cultures that tend to not disclose or accept illness, particularly ones that are sexually transmitted or incurred due to injection drug use, this pattern exerts a dual deterrent to entering care. The 'late to care' pattern as evidenced by seroconversion to an AIDS diagnosis within a year of being diagnosed HIV-positive is most pronounced among African-

Americans, Hispanics, Injection Drug Users, Other Substance Users and the Incarcerated/Recently Released.

Upon entry to primary medical care, the reasons for detachment include inability or unwillingness to maintain a rigorous treatment regimen (one in which adherence should be 94% or more to attain optimal benefit), side effects of HIV medications, the high cost of drugs or the co-payment related to HIV medications, and the pressure of other subsistence needs such as employment, housing and transportation to either access primary medical care or in lieu of paying for primary medical care.

Key points along the Continuum of Care can be assessed in a study specific to the 'Out of Care' to confirm that these are the risk flags for PLWHA considering abandoning their care regimen. Flags include erratic appointment compliance (missing three or more appointments); tendency to not disclose issues, repeated concerns about medication regimens and drug resistance that may be flags for non-compliance with medication regimens. Questioning PLWHA that are 'Out of Care' about their decision to abandon primary medical care will better highlight these risk points.

The Never in Care are one of the most troubling and least known subgroups. This group evidences resistance issues related to initial attachment to care upon positive HIV diagnosis. Subgroups exist within the 'Never in Care' including PLWHA who self-manage (majority are long-term survivors and wary of HIV medications from the first generation of HIV drugs such as AZT), the 'unconnected' which includes undocumented citizens, the Incarcerated/Recently Released, Injection Drug Users and some Substance Abusers. The Never in Care do not wish to expose themselves to any legal ramifications nor change their current patterns of behavior. Entering medical care is perceived as an exposure risk.

C. Project Design

Collaborative Research proposed to survey PLWHA who are 'Out of Care'. Strategies for reaching these individuals included but were not limited to:

- *Working with Primary Care Clinics to identify individuals who are out of care or in danger of going out of care;*
- *Working with local support services agencies to identify individuals who are accessing support services (food bank) and not primary medical care;*
- *Working with Counseling and Testing providers to survey newly diagnosed.*

Collaborative Research offered $20 incentives (Gift Card) and utilize a toll-free 1-800 number for survey respondents to take the survey. Additional OOC individuals were interviewed face-to-face at various sites throughout the EMA.

II. Unmet Need/Out of Care Framework and Survey Methodology

A. The Phoenix EMA's Unmet Need Framework

The Phoenix EMA Unmet Need Estimate

At the time of this writing, only the Arizona total estimate of unmet need was available. A Phoenix EMA-specific estimate of unmet need is not yet available for the 2006 project year, as it is currently in progress. Based upon the 2005 Integrated Epidemiologic Profile, a total estimated number of those 'aware but out of care' is available for both Maricopa and Pinal counties comprising the Phoenix EMA. (See Table 2 below)

Table 2: Total Phoenix EMA Unmet Need Population: In Care vs. Out of Care

Counties of EMA	In Care Clients	% of State's Total	Out of Care Clients	% of State's Total
Maricopa	3524	72.9%	3242	66.4%
Pinal	115	2.4 %	170	3.5%
GRAND TOTAL	3639	75.3%	3412	69.9%

Statewide, 50.2% are reported with an "Unmet Need" according to the 2005 Integrated Epidemiologic Profile. Thirty nine percent (39%) of the PLWHA living in the Phoenix EMA are 'Out of Care' according to the 2005 unmet need estimate.

B. Phoenix Unmet Need Survey Methodology

Table 3 shows the breakdown of the Unmet Need/Out of Care survey respondents by race, gender and sexual orientation.

Table 3: Phoenix EMA 2006 "Out of Care" Survey Sample

Phoenix EMA 2006-Out of Care Respondents	Actual	%
Race/Ethnicity		
Black, not Hispanic	11	18%
Hispanic	7	13%
American Indian	4	7%
Anglo	35	63%
Total	***57***	***100%***
Gender		
Male	43	77%
Female	14	23%
Total	***57***	***100%***
Exposure Category		
MSM	16	29%
Injection drug use (IDU)	8	14%
Men who have sex with men and inject drugs (MMS + IDU)	8	14%
Heterosexual	12	21%
Sex with Drug User	5	7%
Transfusion/Hemophiliac	2	4%
Not classified	6	11%
Total	***57***	***100%***

Collaborative Research conducted the 2006 needs assessment in collaboration with the Phoenix EMA. Out of Care surveys were completed in the Summer of 2006 and administered in person and by telephone through an 800 number. The same individual conducted all interviews. Survey recruitment was done in the following ways:

- Out of Care clients were identified through various AIDS service organizations
- Flyers were widely posted and distributed throughout the EMA to promote self-referrals.

III. 'Unmet Need' Study Findings

Based upon the Unmet Need Framework, the Phoenix EMA undertook a rapid needs assessment process in order to address the following four items, including plans for cross-Title collaboration in these areas:

1. Describe the demographics and location of persons who know their status and are NOT in care;
2. Assess the service needs, gaps and barriers to care, including disparities in access and services among affected subpopulations and historically underserved communities;
3. Describe plans to find people NOT in care and get them into care; and
4. Describe how the results of the Unmet Need Framework were used in planning and decision-making about priorities, resource allocations and the system of care.

The Unmet Need Study findings will address Items 1 and 2 above in the following narrative.

A. Describe the demographics and location of persons who know their status and are NOT in care

1. What subpopulations are most likely to be 'Out of Care'?

Based upon the Phoenix estimate of unmet need and the statewide demographics of those living with HIV versus those living with AIDS who are NOT in care, **White male MSM, followed by White Male IDU are the two populations most likely to be 'Out of Care" with unmet need in the Phoenix EMA.**

2. Characteristics of PLWHA Not in Care

Based upon the unmet need estimate and OOC survey data, it may be inferred that the 'Out of Care' population in the Phoenix EMA is 75% Male and 25% Female. As much as fifty five percent (55%) of the population is likely to be homeless or temporarily housed. The majority are more likely than not to be HIV positive/not AIDS diagnosed. And, based upon the R.A.R.E. survey study, the majority is actively using illicit substances, many of whom report regular use of crystal methamphetamine. In fact, the majority of OOC PLWHA report "active substance abuse" as the primary reason for their delay into primary medical care and/or their major reason for stopping HIV primary medical care.

The Phoenix OOC population includes those who have been erratically in care, those who have dropped out of care for periods of one year and for greater than two years duration. A significant minority of the OOC respondents has yet to enter primary HIV medical care. ***By far, the single greatest variable that negatively impacts successful entry into and retention into HIV primary***

medical care is substance use and abuse. Crystal methamphetamine is the single drug of choice most frequently reported as used by the OOC population.

3. Location of PLWHA with Unmet Need in the EMA

At the time of this writing, there was no current location information (i.e. zip code or county of residence) available for the entire OOC population. However, the zip code of current residence of all the 57 OOC Survey respondents is available and inferences may be drawn from this data and utilized for planning purposes.

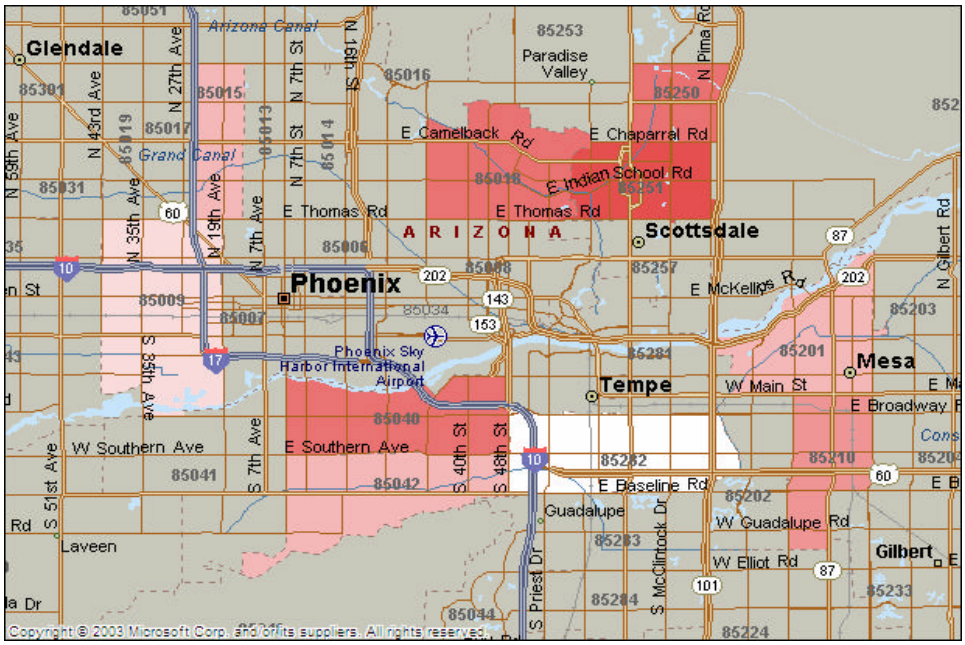
Zip Code of Residence for OOC Respondents

The majority of OOC respondents (60%) report their residence in one of five major zip codes, including85251, 85018, 85040, 85015, and 85201. The remainder of the OOC survey group reports their current residence within five other zip codes within the Phoenix EMA.

Table 4: Residential Zip Codes of OOC Respondents

ZIP	#	%
85015	6	11%
85009	5	9%
85018	7	12%
85251	8	14%
85250	7	12%
85201	6	11%
85040	7	12%
85210	5	9%
85042	5	9%
85282	1	2%
Grand Total	**57**	**100%**

Table 5: Phoenix EMA "Out of Care" Zip Code Map



4. Additional Out of Care Characteristics Inferred from the 'Out of Care' Needs Assessment Study

The 'Out of Care' PLWHA who participated in the unmet need study include 43 Males (75% of the sample) and 14 Females (25% of sample). (See Table 6 below)

Table 6: Gender of OOC Survey Participants

Gender	#	%
Male	43	75%
Female	14	25%
Transgender	0	0%
Total	**57**	**100%**

The transmission risks reported by the OOC respondents include 16 MSM; 8 MSM/IDU; 8 IDU and 17 Heterosexual risk. The reported transmission risks and age ranges of the OOC survey participants are evidenced in Table 7 and Table 8 below.

Table 7: Transmission Risk of OOC Survey Participants

Phoenix OOC	Sexual Orientation	Sample Frame	Sample Frame
		#	%
Transmission	Heterosexual	17	30%
Risk	MSM	16	28%
	MSM/IDU	8	14%
	IDU	8	14%
	Other/PNTA	8	14%
TOTAL		**57**	**100%**

The majority of the Phoenix EMA 'Out of Care' respondents (77%) reported ages in the 25-34 age range (35% of the survey group) and 35-44 age range (42% of the total respondent group).

Table 8: Age Ranges of OOC Survey Participants

Age Range	#	%
0-13	0	0%
13-24	1	2%
25-34	20	35%
35-44	24	42%
45-54	12	21%
55-64	0	0%
65-74	0	0%
TOTAL	**57**	**100%**

Sixty one percent (61%) of the 'Out of Care' survey participants were White; 19% Black and 12% Hispanic. (See Table 9 on the following page)

Table 9: Race/Ethnicity of OOC Survey Participants

	Group	#	%
Race/Ethnicity	Black or African-American	11	19%
	White	35	61%
	American Indian	4	7%
	Hispanic	7	12%
	Other	0	0%
	Total	**57**	**100%**

Significantly, 14 OOC PLWHA (or 25%) of the 57 OOC survey participants report that they are currently homeless and/or residing in a halfway house/treatment facility. Additionally, a sizeable portion of the OOC participants (17 PLWHA or 30%) report being 'temporarily housed', either staying at a parent/relative's house, or staying at someone else's apartment or house.

Table 10: Current Residence of OOC Survey Participants

Residence	Live Now	
	#	%
In apartment/house I own/rent	25	44%
Section 8 housing	1	2%
At my parent's/relative's house	14	25%
Someone else's apartment/house	3	5%
In a halfway house, transitional housing or treatment facility	8	14%
Homeless (on the street/in car)	1	2%
Homeless shelter	5	9%
TOTAL	**57**	**100%**

Time Span Since HIV Diagnosis

The majority of the OOC survey participants represent a group of fairly recently diagnosed HIV infection, with all but five reporting first learning their HIV status since 2000. The remaining five PLWHA report first testing HIV positive in 1998. Sixty five percent (65%) were diagnosed HIV positive in the Phoenix EMA and 35% report their first diagnosis outside the EMA.

Most Recent Primary Medical Care Visit

The OOC respondents report a relatively short period of time since their receipt of some form of primary medical care, ranging from 16% as recently as four months ago; 32% 4-6 months ago; 16% 10-12 months ago; and 16% almost 21/2 years ago. ***Six PLWHA (or almost 10% of the OOC sample) report <u>never</u> having entered care.***

Therefore, the majority of the OOC sample report a varying range of time since receiving HIV primary medical care, with 32% erratically out of care, 10% reporting unmet need of one year duration, and 16% reporting unmet need of two-plus year duration or longer.
Of greatest concern are the six PLWHA (or almost 10% of the OOC sample) who report having yet to enter HIV primary medical care. (See Table 11 below)

Table 11: Time Period Since Last Report of Medical Care

Most Recent Medical Care		
Year	#	%
Last 4 months	9	16%
4-6 months ago	18	32%
10-12 months ago	9	16%
> 1 year	6	10%
> 2 years	9	16%
Never in Care	6	10%
Total	**57**	**100%**

Most Recent Report of Antiretroviral Therapy and Receipt of Laboratory Monitoring Services

When the OOC respondents were asked 'how long it had been since they took antiretroviral medications for their HIV disease', the respondents reported similar relative periods since taking medication than when last in care. Thirty two percent (32%) report last taking ARV therapy at least 4-6 months ago, 32% report taking ARV medications over one year ago, and 16% report last taking ARV medications over two years ago. Ten percent (10%) of the OOC respondents report having NEVER taken antiretroviral medications.

Time since last receipt of laboratory monitoring services, as reported by the OOC respondents, mirrored the same relative pattern as that observed in the reports of last primary care visit and last ARV therapy, as evidenced in Table 12 below.

Table 12: Time Since Last Receipt of Laboratory Services

Most Recent Laboratory		
Year	#	%
Last 3 months	0	0%
4-6 months ago	18	32%
7-12 months ago	15	26%
> 1 year	9	16%
> 2 years	9	16%
Not yet	6	10%
Total	**57**	**100%**

HIV Testing Circumstances

The majority of the OOC respondents' (67%) report first learning their HIV status upon a voluntary request for testing. Ten percent (10%) of the OOC respondents learned their HIV status upon an ER or hospital visit for the treatment of another condition, and 9% learned they were HIV-positive as a result of blood donation. Only 5% report learning their HIV status as part of an outreach testing service and 9% were first tested as part of partner notification services.

Table 13: HIV Testing Circumstances

Discovery Method	#	%
Received testing when asked a health provider to test you for HIV	38	67%
Tested as part of an outreach clinic or street outreach program that offered HIV testing	3	5%
Tested when tried to donate blood/plasma	5	9%
Tested as a result of having sex with someone who was HIV Positive	5	9%
Tested when went to hospital/ER for something else	6	10%
TOTAL	**57**	**100%**

Rates of Referral into Care and Delay from Testing Positive to Entering Care

As is evidenced by the table below, the OOC respondents report receipt of more than one referral, with 98 referral responses noted. Only 27% of the OOC respondents report having been directly referred into HIV primary medical care upon diagnosis. (However, 15% don't know/don't remember to what services they were referred.) An additional 10% report having been referred for Case Management services and 12% of the OOC respondents report being referred for treatment of another condition other than HIV disease. Twenty percent of the respondent group reports referral into substance abuse treatment and 14% report referral into mental health counseling services. Only 1% of all OOC respondents report NO referral for any services whatsoever upon diagnosis.

Table 14: Primary Care Referral Rates

Referred Services	**Total**	
	#	%
Medical care related to the HIV diagnosis	26	27%
Medical care for a condition other than HIV	12	12%

Substance abuse counseling/treatment	20	20%
Mental health services (other than substance abuse counseling)	14	14%
Case Management services	10	10%
No, I was not referred for services	1	1%
Don't know or Don't remember	15	15%
TOTAL	**98**	**100%**

Table 15: Time Between Testing and Entry Into Care

Time to receive medical care	Total	
	#	%
Immediately	0	0%
Within 3 months	6	10%
Within 6 months	6	10%
Within a year	20	35%
Longer than 1 year	19	34%
Have Yet to Enter Care	6	10%
TOTAL	**57**	**100%**

The majority of the OOC respondents (79%) report delaying entry into care following initial diagnosis. Only 10% of all OOC respondents report entering primary care in the optimal three month time frame. Ten percent (10%) of the OOC respondents report a delay of six months, and 35% report initially delaying entry into care within the first year following diagnosis and 34% report delaying entry into care for more than one year.

As previously noted, 10% of the OOC sample have yet to enter care. Table 16 below evidences the reasons offered by the 25 OOC respondents who reported a delay into care.

The majority of respondents who delayed their entry into care cite active use of substances as the reason for their delay. Other reasons offered by the OOC respondents to explain their delay into care include: "Don't trust Doctors" (12%); "Don't like the way I was treated" (4%); and "Don't know where to go for medical care" (4%). Interestingly, none of the OOC respondents reported inability to afford medical care or transportation difficulties as the primary reasons for delaying entry into medical care.

Table 16: Reasons for Delaying Entry into Primary Care

Reasons for delay > 1 year of medical care	Total	
	#	%
Can't afford it.	0	0%
Don't need medical care	0	0%
Can't get transportation	0	0%
Don't know where to go to get medical care	1	4%
Don't trust doctors	3	12%
Don't think I need it	0	0%
Depressed	0	0%
Don't like the way I was treated	1	4%

Actively using Substances	16	64%
Other	4	16%
TOTAL	**25**	**100%**

Reason for Stopping Care

When asked why they 'stopped' medical care, the OOC respondents supplied one or more of the reasons listed in Table 17 on the following page. ***The largest segment of the OOC population (18 respondents or 35%) reported "actively using substances" as their primary reason for dropping out of care.*** An additional 12% reported "had trouble with medications" and 16% report a health professional told them to stop care/take a break from care as their reason for withdrawing from care. Another 15% of the OOC population report having been 'in jail' as the reason for their stopping care. Nineteen percent of the OOC respondents stated "was undetectable" to support the reason to leave care and another 2% (one individual) stated they "decided on their own to take a break". Only one PLWHA reported "felt better" as the reason for dropping out of care.

Table 17: Reasons for Stopping Care

Reason	#	%
Was told to by doctor or nurse	5	10%
Was told to take a break	3	6%
Felt Better	1	2%
Was in jail	8	15%
Decided to take a break	1	2%
Was undetectable	10	19%
Had problems with medications	6	12%
Couldn't afford medications	0	0%
Actively Using Substances	18	35%
TOTAL	**52**	**100%**

Reasons Why PLWHA Don't Get Medical Care for Their HIV

When queried in a differently worded question, the OOC respondents reported reasons to explain why PLWHA do not seek HIV medical care. ***The answer "Actively using Substances" was the most frequently reported reason (17 respondents or 39% of the reasons) why PLWHA are not in primary medical care.*** 'Other reasons' cited by 12 OOC respondents included the "Fear of telling someone else" and "Cultural issues" were cited by seven respondents as the reason PLWHA do not seek medical care for their HIV disease. Communication difficulties, transportation issues, financial concerns and "materials/instructions are confusing" ranked as infrequent reasons to remain out of care, cumulatively reported by 18% of the OOC respondents.

Table 18: Reasons Why PLWHA Do Not Seek HIV Medical Care

Reasons	#	%

Fear of telling someone else	12	27%
Feel healthy	0	0%
Can't afford it	1	2%
Don't have transportation	2	5%
Material/ instructions are confusing	1	2%
Communication difficulties	4	9%
Actively Using Substances	17	39%
Cultural issues	7	16%
Total	**44**	**100%**

Recommendations by PLWHA to Ease Re-Entry Into Care

Not surprising is the fact that 14 OOC respondents (41% of the motivators cited) reported that the availability of substance abuse treatment would motivate re-entry into care. It is interesting to note that only six OOC respondents reported that higher quality services/better trained doctors and nurses would influence their decision or improve their ability to re-enter care. Four respondents (or 12% of all motivators reported by the OOC respondents) cited "transportation as a prompt to re-enter care. Ten respondents (29% of all reported motivators) reported "Nothing" would motivate them to re-enter care. None of the OOC respondents cited insurance, free medical care, more government services or more outreach as motivating factors in their decision to re-enter primary medical care.

Table 19: Motivators to Ease Re-Entry into HIV Medical Care

Motivators	#	%
Transportation	4	12%
Acute illness		0%
Free medical care		0%
Insurance		0%
Better quality of services	3	9%
Referrals or advice		0%
More information about services		0%
Better trained doctors and nurses	3	9%
Employment opportunities		0%
Substance abuse treatment	14	41%
More outreach services		0%
More government services		0%
Nothing	10	29%
Total	**34**	**100%**

Substance Use

As is readily apparent in the previously discussed survey findings, substance use and abuse acts as a serious deterrent to both entry into and retention in HIV primary medical care among the Phoenix EMA 'Out of Care' survey respondents. A substantial majority of the OOC survey respondents (30 of 57 respondents) admits to regularly using alcohol and/or drugs not prescribed by a physician on a

relatively frequent basis. ***Fourteen respondents (or 25% of the entire OOC population) reports regular use of crystal methamphetamine.***

Eight respondents admit to previous injection drug use and four respondents report current injection drug use. Three of these respondents admit to "sometimes" sharing needles when injecting substances, but also report cleaning their works.

Table 20: Frequency of Reported Substance Use Among OOC Respondents

	Frequency				
	Daily	Weekly	Monthly	Prefer Not to Answer	Total
Substance					
Alcohol	15				15
Cocaine	8	5			13
Crystal Meth	6	5	3		14
Heroin			3		3
Tobacco	30				30
Total					

Communicable and Other Disease Co-Morbidity

The OOC respondents report a high (65%) co-morbidity rate of sexually transmitted and other communicable diseases. The most frequently reported communicable diseases include Syphilis, Gonorrhea, and Hepatitis.

Table 21: Communicable Disease Reports of OOC Respondents

Communicable Disease	Total	
	#	%
Chlamydia	1	3%
Genital warts		0%
Gonorrhea	10	27%
Hepatitis (ABC)	10	27%
Genital herpes	1	3%
Syphilis	15	41%
TOTAL	**37**	**100%**

The Phoenix OOC respondents report relatively few other disease states. Reported illnesses (among the 11 reports of diagnosed diseases) include Emotional Problems (27%); PCP pneumonia (18%); Neuropathy (18%); and Cancer (9%); Liver problems (9%); Lung problems (9%); and Problems with Thought or Memory (9%).

Table 22: Chronic Disease Reports of OOC Respondents

Disease	#	%
Cancer	1	9%
Liver Problems	1	9%
Lung/Breathing Problems	1	9%

Neuropathy	2	18%
PCP Pneumonia	2	18%
Problems with Thought or Memory	1	9%
Emotional Problems	3	27%
None or Don't Know		0%
TOTAL	**11**	**100%**

Thirty three percent (33%) of OOC respondents report taking one or more medications for their physical illness (other than HIV meds) and 17% of the OOC respondent reports taking some type of medicine for their mental illness.

B Assess the service needs, gaps and barriers to care, including disparities in access and services among affected subpopulations and historically underserved communities

A service Need ranking and Gap ranking (services needed but perceived as unavailable) was developed for ALL Out of Care respondents.

Service Needs

Needs	Sum of Out of Care survey respondents who answered 'Yes' to Need (1 is highest ranking)

Table 23: Top Ranking NEEDS of ALL OOC Respondents

Service Category Description	Need Rank
Housing Assistance	1
Clothing	2
Food	2
Translation	2
Transportation	2
Hospitalization	2

The top six ranking service NEEDS reported by the entire 'Out of Care' respondent group include primarily 'supportive services': Housing, Clothing, Food, Translation services, and Transportation. Hospitalization is also listed as a needed service. (It is not clear from the data whether this service relates to physical health issues or substance abuse treatment needs.)

Service Gaps and Reasons for Gaps

Gap	Sum of Out of Care survey respondents who listed a NEEDED service as UNAVAILABLE

Service Category Description	Gap Rank	Reason Gap
Housing assistance	1	Not available to Spanish Speakers
Clothing	2	Lack of information on where to obtain
Food	2	Hard to find access
Translation services	2	
Transportation	2	No funding for transportation
Hospitalization	2	Cannot get if do not have Social Security number

The Service Gaps listed by the Phoenix 'Out of Care' population (services needed but perceived as unavailable) include a mixture of 'essential' core services and 'supportive' services. A lack of awareness of exact service location and/or how to access needed services and the lack of funding/insurance/underinsurance are cited by OOC respondents as reasons impeding access to care and services. Lack of translation is perceived to be at least part of the reason for the perceived unavailability of needed housing services.

C. Describe Plans to Find People NOT in Care and Get Them into Care

Addressing the 'Unmet Need' is the most important aspect of the Unmet Need Framework and process. The strategies developed and implemented to address Unmet Need should:

1. Ensure equitable access to care regardless of OOC population characteristics or location within the service area;
2. Effectively help the OOC into care;
3. Effectively retain them in care;
4. Ensure that supportive services contribute to primary care entry and retention in care. (Mosaica Unmet Need TA Center of the TAC, June 2006 Meeting with Title I and Title II Programs)

Different strategies will be necessary for different sub-groups of PLWHA. For example, different strategies will be necessary for the Newly diagnosed, for PLWHA receiving medical and supportive services other than primary HIV medical care, for those PLWHA who have either 'erratically' been in care or who have dropped out of care, and for those PLWHA who have NEVER been in care.

The chosen intervention strategies must effectively close the identified Gaps in needed services and may require some changes to the existing continuum of care in the Phoenix EMA.

Suggested Strategies for Newly Diagnosed PLWHA:

Improved links between prevention and care, such as:

1. *Locating HIV Testing programs in HIV primary clinics, with aggressive offers of testing to the Patients' sexual and drug-using partners, spouses, and*
2. *Use of rapid testing in clinical and outreach testing settings*
3. *Use of peer outreach testing specialists to locate and test other high risk individuals within their own unique social networks*
4. *Implementing same day referrals into primary medical care upon testing positive*
5. *Use of peer mentors to ease transition into care and assist with navigation of care systems (Adapted from Mosaica TA Information, 2006)*

Suggested Strategies for PLWHA Receiving Some Services But NOT Primary HIV Medical Care

Improved Linkages Between Supportive and Primary Care Services

1. *Case Managers and other Support staff who provide services should inquire about and encourage entry/re-entry into primary medical care*
2. *Case Managers and Therapists should ensure that the necessary supportive services are provided to stabilize the person's life situation (i.e., stable housing, food, safety) and then help ensure that these services are extended to facilitate entry into and retention in care, as indicated*
3. *Use of active referrals into primary medical care with documented confirmations of Intake appointments/Re-Establish appointments*

(Adapted from Mosaica TA Information, 2006)

Suggested Strategies for PLWHA Who Have Dropped Out of Care

Improved Provider-Patient Partnerships and Collaborations with Peers

1. *Primary Care providers should make appointment reminder calls; facilitate transportation assistance; and implement/maintain "no-show" tracking and follow-up protocols*
2. *At least biannually, Primary Medical providers should examine patient lists to determine who has not returned for care and initiate telephone and/or letter contact to make appointments and encourage re-entry into care*
3. *Use of peer advocates to get PLWHA back into care*
4. *Focus on reducing known barriers to care and resolving gaps in continuum of care*

(Adapted from Mosaica TA Information, 2006)

Suggested Strategies for PLWHA NEVER in Care

Peer-facilitated Linkages Between Points of Entry/Testing/Counseling & Primary Care

1. *Active follow-up by Testing/Counseling agency to maintain contact/ confirm entry into care*

2. Peer Outreach to specific populations and locations, including homeless shelters, etc
3. Regular marketing of primary care services' availability and directions on making referrals with all points of entry staff and agencies
4. Social marketing efforts regarding benefits of care and treatment
(Adapted from Mosaica TA Information, 2006)

Summary

In summary, the persons living with HIV/AIDS in the Phoenix EMA who are most likely to be out of care include White Male MSM, followed by White Male IDU. Blacks are disproportionately impacted among the OOC populations, particularly among the risk groups of MSM and IDU, when their representation in the local epidemic and proportion in the general population is considered. When HIV status is considered, Males with HIV are most likely to be out of care; however both men and women who are living with HIV are equally as likely to be out of care and women disproportionately so.

The majority of OOC respondents (60%) report their residence in one of five major zip codes within the EMA. The OOC population evidences a group of persons with a significant level of homelessness and/or temporary housing.

The Phoenix OOC population includes those who have been erratically in care, those who have dropped out of care for periods of one year and for greater than two years duration. A significant minority of the OOC respondents has yet to enter primary HIV medical care. ***By far, the single greatest variable that negatively impacts successful entry into and retention into HIV primary medical care is substance use and abuse. Crystal methamphetamine is the single drug of choice most frequently reported as used by the OOC population.*** *The 'motivators' most frequently cited by the OOC population which would prompt re-entry into care included "Substance Abuse Treatment",* "Transportation", "Higher quality services", and "Better trained physicians and nurses". The top six ranking service NEEDS reported by the entire Out of Care respondent group include Housing Assistance, Clothing, Food, Translation, Transportation, and Hospitalization..

The Service Gaps listed by the Phoenix 'Out of Care' population (services needed but perceived as unavailable) include primarily the 'supportive' services (and not 'essential' services, with the exception of hospitalization). A lack of awareness of exact service location and/or how to access needed services and the lack of insurance/underinsurance are cited by OOC respondents as reasons impeding access to care and services. Funding levels are perceived to be at least part of the reason(s) for the perceived unavailability of needed services. Lack of available

transportation, particularly medical transportation assistance to physician appointments is a cited gap. A perceived lack of access to translation assistance is another cited gap in services within the EMA.

Different strategies will be necessary for different sub-groups of PLWHA. For example, different strategies will be necessary for the Newly diagnosed, for PLWHA receiving medical and supportive services other than primary HIV medical care, for those PLWHA who have either 'erratically' been in care or who have dropped out of care, and for those PLWHA who have NEVER been in care.

Additionally, it is important to delineate specific continuum of care plans for each of the major Special Populations in the EMA. The chosen intervention strategies must effectively reduce the identified barriers to needed services and may require some changes to the existing continuum of care in the Phoenix EMA.